



An inspirational guide
for people living with dementia

SERIES 1

Introduction

How we live our lives, or the lifestyle choices we make, can play an important role in maintaining good health and preventing illnesses. When diagnosed with dementia, a healthy lifestyle also becomes important in maintaining functioning, coping with stress, and “living well” with the disease. Research suggests that we may be less likely to develop dementia and tolerate changes experienced, if we eat a diet that is rich in antioxidants, control or manage our cholesterol, exercise regularly, keep mentally active, and have supportive social networks. This guide, the fourth in a series, focuses on how enhancing physical, psychological and emotional, social and spiritual well-being can help us live our lives to the fullest extent, even after a diagnosis of dementia.

Although we will be referring to physical, psychological and emotional, social and spiritual wellness separately in this guide, in reality, all of these components of our lives overlap and are intertwined. Therefore, it is important to treat your mind, body, and soul as a whole. This is of the utmost importance so we can be the best we can be every day.

Introduction continued

Two factors are important to enhance wellness for people living with dementia: being proactive and establishing routines. Being proactive allows you to take control of your life, which is a win-win situation. In gaining control you are in a position to not only improve the quality of your life, but also live a purposeful life. Further, developing healthy habits and creating routines will help keep you on track. Although it takes time to begin new routines, it will be worth it and will benefit you in the end because your daily routine can help you be the best you can be every day. Situations constantly change - that is okay. Reassess your personal situation on a regular basis to make the necessary arrangements.

Finally, continue to try to adapt to the levels of your present capabilities. Although this is a gradual and ongoing process, it is important to keep the life scales weighing in your favour!

– Brenda Hounam, Paris, ON

This booklet is dedicated in loving memory to my beautiful little granddaughter, **Leah Jennifer Whitney**

Maintaining physical well-being

You are what you eat

Healthy eating is an important element in maintaining, and enhancing wellness – a good diet leads to a clear mind. Eating well does not mean that you have to cut out everything that you enjoy; however, enjoy them in moderation.

Suggestions to consider in developing healthy eating habits

These suggestions are provided by people living with dementia. Please consult your doctor or registered dietitian before making any changes to your diet.

- ✓ Eat foods rich in omega-3 fatty acids. Food rich in omega-3 include olive oil and flaxseed oil, fish, including salmon, herring, mackerel, anchovies and sardines, raw nuts and seeds.
- ✓ Drink red wine in moderation.
- ✓ Drink green tea.
- ✓ Enjoy foods rich in antioxidants, such as blueberries and pomegranates.
- ✓ Eat dark chocolate (75% or higher raw cacao content).

Maintaining physical well-being continued

Suggestions to consider in developing healthy eating habits

- ✓ Eat smaller amounts more often, avoid processed foods and use spices to limit salt.
- ✓ Drink water. Becoming dehydrated can result in increased memory problems and confusion.

Suggestions for daily food intake

- ✓ Vegetables - leafy greens (e.g., lettuce, spinach, mixed greens, kale, cabbage) and cruciferous vegetables (e.g., broccoli, cauliflower, brussels sprouts, kale, cabbage, bok choy).
- ✓ Fruit - berries (fresh or frozen).
- ✓ Whole grains (e.g., oats, brown rice, brown pasta, 100% whole wheat or whole grain breads, quinoa, bulgur, barley, whole grain pasta) instead of refined grains (e.g., white rice, white pasta, white bread).
- ✓ Dairy - low-fat milk (skim or 1%), yogurt (0-2%), and cheese (about 22%).
- ✓ Meat and poultry.

Maintaining physical well-being continued

Suggestions for daily food intake

- ✓ Fatty fish or seafood, not battered or fried (e.g., salmon, trout, sardines). Unsalted nuts (walnuts) or all-natural nut butters (e.g., almond butter, peanut butter).
- ✓ Beans or legumes (e.g., chickpeas, kidney beans, lentils, navy beans).
- ✓ Extra-virgin olive oil for cooking.



For more information on healthy eating habits, refer to the By Us For Us guide: **Food and Mealtime** and the Resources and References section of this guide.

Notes

“My wife and I make a point to prepare the evening meal together and to enjoy eating it together. Have cut out sugar intake, better balanced meals, less meat and more fish. Feel better/more positive.”

(David Knight, early-stage support group member,
Alzheimer Society of Guelph)

Maintaining physical well-being continued

Taking care of your body

In order to take care of your body, you need to be proactive. This means researching and understanding your previous and current health conditions, understanding the effects of your diet, being knowledgeable about the medication you are taking, and being active in making decisions related to your health care.

Things to consider for a healthy body

- ✓ Control and monitor your cholesterol and blood pressure. Untreated, they can negatively affect your brain health. Use diet and exercise to control these health issues.
- ✓ If you need medication to control blood pressure, cholesterol or for any other reason, understand the medication you are taking, how they interact with other medications, and potential side effects.
- ✓ Don't forget to rest. Napping is a great way to feel refreshed – a quick nap in the afternoon works great.
- ✓ Visit your doctor regularly and take your medication as prescribed. Work with your doctor to take care of your body.
- ✓ Exercise your brain daily. For example, reading the newspaper or completing a crossword every morning can be a great routine to establish and is a great way to keep your brain active.

Maintaining physical well-being continued



For more ways to exercise your brain, refer to the By Us For Us guide: **Memory Work Out.**

Being active

The World Health Organization maintains that being physically active can assist in the management of dementia. In fact, research suggests that physical activities are important for maintaining or enhancing cognitive functioning as we age. Simple activities, including taking a walk outside or inside on rainy days, weeding the garden, mowing the lawn, or biking can be beneficial in many ways. For example, being active can reduce the risk of depression and provide a sense of social, psychological and emotional well-being. It can also help to maintain a healthy weight, lower blood pressure and cholesterol levels, and help you sleep better – all of which can have a direct impact on brain health.

You need to like what you are doing, however, or else you will not keep up the routine. So, choose something that you enjoy. Challenge yourself in a variety of ways through physical activity – it will make your routine more enjoyable and more likely that you will continue doing it.

“I as a person have not changed...only my mind.”

(Eileen Stevenson, early-stage support group member,
Alzheimer Society of Niagara Region)

Maintaining physical well-being continued

Things to consider to enhance physical well-being

- ✓ Consult your doctor before starting a new exercise routine.
- ✓ Walking up and down your stairs at home can provide an easy and inexpensive cardio workout.
- ✓ Swimming and aqua fit classes are low impact and easy on the joints and a great form of resistance training. Aqua fit also allows for socialization.
- ✓ Dancing is a great form of exercise and can also provide mental and social stimulation, for example, learning ballroom dancing requires that you remember steps and it is done with a partner.
- ✓ Take up tai chi or yoga. They are both forms of relaxation and can also provide mental stimulation because it is necessary to remember the routine.

“About one year ago after returning from the cottage, I noted I was gaining weight. My son suggested I should walk at least 4 times a week about 3.2 km. Being close to Stone Road Mall, I can walk inside and OUT year-round.”

(Moe Freeman, early-stage support group member,
Alzheimer Society of Guelph)

Beyond the physical

Being centred

Psychological and emotional health are just as important as physical health. Dealing with grief and loss is an issue that most of us deal with, especially after diagnosis. And as our abilities change throughout the progression of dementia, we may continue to experience grief and loss. Learning how to live with and transform grief and loss are extremely important. Likewise, we need to minimize stress to maintain a healthy lifestyle. Be careful not to put yourself in situations where you will encounter stress, and keep your emotions in check. This will help in maintaining a level existence. If you cannot avoid stress, try to keep it short term if possible, and learn coping strategies that help you manage the stress in your life.

Notes

**“Create happiness for others...as a result you’ll
feel happy too.”**

(John Stulen, early-stage support group member, Alzheimer Society of Brant, and the John Noble Home, Day and Stay, Lead Program)

Beyond the physical continued

Things to consider to enhance psychological and emotional well-being

- ✓ Don't be ashamed of your dementia, it is a medical condition the same as any other. As people living with dementia, we need to teach others how to support us. Let people know you have dementia; often they will be more considerate and understanding. Don't be afraid to ask for help.
- ✓ Accept your new reality and allow yourself time to grieve.
- ✓ Allow for emotional release. It is part of the grieving process and is healthy, as long as there is a balance between feeling down and being positive.
- ✓ Keep a journal of your feelings.
- ✓ Try to let things go and do not allow your emotions to build inside you. End or minimize negative relationships.
- ✓ Do not worry about making mistakes and forgive yourself if you do.
- ✓ Do things that allow you to feel a sense of purpose and contributing – even something small like peeling potatoes provides a sense of contributing and is an emotionally uplifting thing. It can also help you feel like a member of the family.

Beyond the physical continued

Things to consider to enhance psychological and emotional well-being

- ✓ Participate in meaningful leisure activities. Research demonstrates that older adults who participate in leisure activities are happier and more content, are more satisfied with their lives, and have lower levels of psychological distress, anxiety, depression, and negative emotions.
- ✓ Try to be the best you can and do something positive every day.
- ✓ Accept that dementia may cause you to say and do things that may not be appropriate sometimes – people living with dementia and care partners need to be tolerant of those situations.

“My husband was finishing my words, finishing my thoughts. I took him aside privately and said it wasn’t helping. I said I know you are trying to help, but it’s just making me mad, if I stumble around let me, it was only making me frustrated. Unless you tell a person, ‘this is not helping me’, they don’t know. Inside I was really struggling, if you don’t tell them – you have to speak how you feel.”

**(Yvonne Braet, early-stage support group member,
Alzheimer Society Sarnia-Lambton)**

Beyond the physical continued

Things to consider to enhance psychological and emotional well-being

- ✓ Pets and children are very therapeutic. They give us love, don't judge us and know when we're having an off day.
- ✓ Avoid self-pity. Laugh and smile, give and receive hugs every day.
- ✓ Enjoy the little things that life has to offer. We cannot change what has already past, so focus on today, and don't worry about tomorrow because tomorrow has not yet come.

Staying connected

Social engagement and support help to reduce the impact that stressful life events, such as coping with the diagnosis of dementia, can have on well-being as we age. Know and appreciate how important family and friends are to your overall health and well-being. We can utilize our family and friends by working together and openly communicating needs and expectations. Being socially active is fun, it keeps you active, provides mental stimulation, maintains language skills, connects you with people with similar interests, and provides companionship and a sense of accomplishment.

Beyond the physical continued

Things to consider to enhance social well-being

- ✓ Push yourself to be socially involved – recognizing our limits and communicating those limits to our family and friends.
- ✓ Embrace your moments of ‘built-in happiness’, share those things with your care partners so they can bring them up with you when you are feeling down.
- ✓ Embrace your personal support network. Your family and friends are so important – identify one person who can be your trusted friend so you can vent to them when needed.
- ✓ Get out and live – go to a movie, the theatre, out for dinner, shopping, or volunteer.
- ✓ Do things that allow you to engage with other people, for example, consider joining a bridge club, go bowling, entertain, go to a place of worship, join a social group or a sporting team, go dancing, exercise at a gym, or attend an adult day program.

Beyond the physical continued



For tips on how to communicate with family and friends and how to stay socially connected, refer to the By Us For Us guides: **Enhancing Communication** and **Isolation and Enhancing Social Connections**.

Living in peace

Continue to live your life with basic fundamental core values and do those things that give you inner peace, for example, some people find meditation helpful. Also, try to live your life with a sense of purpose. Get involved – become a volunteer, or join a group. Keep living life! Maintaining spiritual well-being allows you to find inner peace, gives you purpose and pleasure, helps others, can be instructional and inspirational, can enhance relationships with others, can provide faith and hope, can be relaxing, and can provide stimulation and a sense of security.

“My wife and I have contact with a wider group of people. These people have similar problems to us; we feel less alone.”

(Moe Freeman, early-stage support group member,
Alzheimer Society of Guelph)

Beyond the physical continued

Things to consider to enhance spiritual well-being

- ✓ Live a good life and do right by other people.
- ✓ Pray, attend a place of worship or watch/listen to religious programming from home.
- ✓ Join a religious club or get involved in a spiritual community. Have faith, meditate or reflect on life, listen to music or read a book.
- ✓ Spend time with family and friends.
- ✓ Help others or volunteer in your community. Spend time outdoors, take a hike.
- ✓ Take time for yourself, solitude is a good time for reflection.

“The first time I couldn’t say the “Hail Mary” I cried. That is when I began meditating. Religion is just a word, meaning ‘to bond us to something’. Going to church is not the only way. Do what suits you.”

(Gail Robinet, early-stage support group member, Alzheimer Society of Brant, and the John Noble Home, Day and Stay, LEAD Program)

Brenda's story: The inspiration behind the By Us For Us Guides

When Brenda Hounam was diagnosed with Alzheimer's disease at the age of 53, she realized that very little information was available for people living with dementia. The dominant view was that people living with dementia could no longer learn and be involved in their own care. Brenda knew differently. In 2003, she was inspired to address this gap - to develop a series of resources specifically designed by and for people living with dementia. In 2004, she approached two of her peers with her idea and was surprised by the enthusiasm and support they offered. Through Brenda's contacts at the Alzheimer Society of Brant, the Alzheimer Society of St. Thomas, and the Murray Alzheimer Research and Education Program (MAREP), Brenda connected with various people living with dementia from all around Ontario to work on what came to be called, the By Us For Us (BUFU) guides. These guides provide tips and strategies for managing daily challenges and enhancing well-being for themselves and others living with dementia. Since the publication of the first guide, "Memory Workout", the following guides focused on issues raised by people living with dementia. The project has grown to include three series researched and developed in partnership with people living with dementia and care partners. The philosophy of the By Us For Us guides remains committed, placing importance first on the experiences, suggestions, and tips from those directly affected BY dementia, FOR those directly affected. Brenda has been a true inspiration and role model to her peers. Without her determination and perseverance, this project would not exist or have the international recognition that it does.

Resources

Alzheimer Society of Canada

Toll-free telephone: 1-800-616-8816

Email: info@alzheimer.ca

Website: www.alzheimer.ca

Canada's Food Guide

Website: food-guide.canada.ca

World Health Organization

Website: www.who.int

We also suggest that you check for other local, national and international resources.

Endorsements

I continue to be impressed with the work this group has completed. The basic message is positive thinking. This, in fact, holds true for all illnesses. The benefits of positive thinking have been shown in scientific studies and can affect a range of hormones that impact on the immune system as well as other organ systems. In addition, this guide promotes personal responsibility for health including lifestyle choices such as proper diet, exercise, discontinuation of smoking, weight control and responsible alcohol consumption. These factors not only influence disease states such as dementia, but also improve self esteem which also affects health. I support this guide wholeheartedly and encourage all individuals, both those with and those without dementia, to read and then re-read this booklet. Take one step at a time and don't feel discouraged if you can't do everything. Every little bit helps.

E. Anne Braun, M.D., M.Sc., F.R.C.P.(C), F.A.C.P.

Associate Clinical Professor Medicine & Psychiatry McMaster University Geriatrician

I would like to offer my congratulations to the “By Us For Us” team for providing these wonderful tools for living and wellness. The recommendations made by the members of the team not only provide a guide for persons living with the day to day challenges of dementia, but a recipe for successful living for everyone. One needs to ‘treat your mind body and soul as a whole” according to Brenda and be proactive when it applies to our health. Developing healthy habits and routines will create a purposeful lifestyle and improve quality of life. The tips and strategies and wellness promotion in the Enhancing Wellness guide provides a concise plan to enhance general well-being.

As an educator and program director of the Day and Stay Program an adult day service, which offers three special programs for persons with dementia, I use the “By Us For Us” guides with students learning about dementia as well as caregivers who come to us for help. The previous guides have been extremely beneficial and I am excited about having two new tools to use when advocating for understanding the needs of individuals with dementia. Maximizing strengths, focusing on abilities and wellness is the key to living with an illness causing memory loss and the strategies. The guides provide suggestions from persons living with the challenges of dementia to help others who are on the same journey. It has been my privilege to get to know some of the individuals who have worked so hard to put the five guides together. I thank each and every one of you for sharing your experience on the challenges you face daily and for having the courage to develop the “By Us For Us” guides. The resources you have put together will truly make a difference in the lives of those touched by memory loss.

Carol Howarth, RN, BScN., GNC(C)

Coordinator, Day and Stay Program John Noble Home

The “By Us For Us” guides have been requested and used by persons with dementia, family members and professional care partners across the world. They are so widely sought after because they provide relevant information based on the “lived” experiences of those living with memory loss and they present that information in an accessible way. I want to thank Brenda Hounam and all of the individuals living with memory loss who have contributed to the guide by being willing to share with others their experiences and the ways in which they “live” with dementia. You are an inspiration to us all. And, all of us can learn how to enhance our own wellness from this guide.

Sherry L. Dupuis, Ph.D. Director,
Murray Alzheimer Research and Education Program Associate
Professor, Department of Recreation and Leisure Studies
University of Waterloo

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The development team

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References

Parrott, M., & the Canadian Consortium on Neurodegeneration in Aging. (2017). Which foods help the brain? An evidence-based approach to healthy eating for the Aging Brain. Retrieved from www.baycrest.org

About the By Us For Us Guides

The By Us For Us Guides (BUFU guides) are designed to provide people living with dementia/care partners the necessary tools to enhance their well-being and manage daily challenges. What makes these guides unique is that they are created BY people living with dementia/care partners, FOR people living with dementia/care partners. The guides include three unique series:

People Living with Dementia: Series 1

This series is written by people living with dementia and covers their experiences. It includes topics such as tips and strategies for managing daily challenges, memory exercises, and enhancing communication and wellness.

Partnership: Series 2

This series is written by both people living with dementia and care partners and covers the partnership experience. It includes topics such as safety, food and mealtimes, social connections, and coping with loss and grief.

Care Partner: Series 3

This series is written by care partners and covers their experiences of supporting a person living with dementia. This series includes topics such as before diagnosis, young care partners, roles, and health and wellbeing.

**To view other guides or order print copies, please visit the Schlegel-UW Research Institute for Aging website:
www.the-ria.ca**

We welcome your input...

If you are living with dementia or are a care partner and would like to comment on this guide, suggest topics for future guides, or participate in future guides, please contact Murray Alzheimer Research and Education Program (MAREP).

Connect with us!

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